Health Status Assessment Project – First Year Results

The Health Status Assessment Project is a three-year longitudinal survey that will allow the Managed Risk Medical Insurance Board (MRMIB) to evaluate the health status of children newly enrolled in the Healthy Families Program. The project examines the physical and psychosocial benefits of having access to comprehensive medical, dental and vision insurance.

The project is being conducted by MRMIB in partnership with researchers at the Center for Child Health Outcomes, Children's Hospital and Health Center, San Diego. Financial support is provided by the David and Lucile Packard Foundation.

The methodology used to assess changes in health status is based on recommendations from the HFP Quality Improvement Workgroup. The Workgroup selected the PedsQL™ 4.0 (Pediatric Quality of Life Inventory™ Version 4.0) as the tool to measure health status.

The PedsQL™ is a simple questionnaire that asks children (ages 5-18) and their parents (of children ages 2-18) about their perceptions of the child's health-related quality of life. The survey asks how much of a problem each item has been during the past one month.

A 5-point response scale is utilized (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Higher scores indicate better health-related quality of life.

The survey procedure includes the initial survey mailing, reminder postcard mailing, non-response second survey mailing and non-response phone follow-up.

The tool was selected because of its length (23 questions), short time to complete and the ability to use the instrument for all Healthy Families Program age groups.

Research has shown that health-related quality of life surveys are a reliable and valid measure of health status and that parent's perception of their child's health is a reliable indicator of the child's health status. (A detailed description of the PedsQL™ 4.0 is included as Appendix A)

Survey Design

The study was conducted by mailing the PedsQL™ 4.0 questionnaire to subscribers and their parents during the subscribers first month of enrollment. Twenty-thousand (20,000) subscribers who were newly enrolled in the months of February and March 2001 were selected for the survey. Questionnaires were mailed to the families in five languages (English, Spanish, Vietnamese, Korean or Chinese) based on the language of the applicant.

Results of the returned questionnaires were compiled and analyzed to develop a **baseline** measurement of health status. The identical questionnaire was mailed during February and March of 2002 to the sample subscribers who remained in the HFP over the one-year period or **year 1.** The data collected for **year 1** was compared with the **baseline** data to measure changes in health status.

Survey Measures

Demographic variables examined in this study include age, gender, language, ethnicity and the presence of a chronic health condition. In addition to demographic variables, the relationship between a subscriber's use of services and health-related quality of life was examined.

I - Survey Sample

Response Rates

Packets containing the PedsQL™ 4.0 survey instrument were mailed to 20,031 families during February and March 2001. A total of 10,241 families (51%) returned the baseline survey.

Of these 10,241 members surveyed during their initial month of enrollment, 6,881 (67%) remained in the Healthy Families Program for one year. This retention rate (67%) is similar to the experience of the entire Healthy Families Program population.

- **Of the 6,881 respondents remaining in the program after one year, over 87% (6,005) completed the year 1 survey.**

The ethnicity, language, age and gender distribution of the sample matches those of the overall HFP population.

African-American and White parents were *less* likely to complete the survey, and Latino and Asian/Pacific Islanders parents were significantly *more* likely to complete the survey.

English survey respondents were less likely to complete the survey and Spanish survey respondents were more likely to complete the survey.

Table 1 presents the sample characteristics by age, language and ethnicity of the survey response rates for baseline and year 1.

Table 1. Sample counts and response rates by age, language and ethnicity

	Baseline		Year 1	
	Response Rate	% of Sample	Response Rate	% of Sample
AGE				
Toddler (2-4)	59%	30.5%	89%	19.45%
Young Child (5-9)	48%	24.3%	87%	25.98%
Child (8-12)	50%	31.4%	87%	35.20%
Adolescent (13-16)	47%	13.8%	87%	19.57%
LANGUAGE				
English	44%	43.0%	83%	38.57%
Spanish	58%	50.7%	91%	53.91%
Chinese	58%	3.3%	84%	1.43%
Korean	55%	1.7%	85%	2,31%
Vietnamese	56%	1.4%	85%	3.98%
ETHNICITY				
White	46%	13.7%	82%	12.61%
Latino	53%	61.5%	89%	62.21%
Black/African-American	37%	2.3%	79%	1.92%
Asian/Pacific Islander	54%	11.8%	82%	12.36%
Native American	46%	0.4%	89%	.4%
Not Reported	50%	10.3%	85%	9.84%

Note: Language refers to language of questionnaire

Retention Rates After One Year

Table 2 on page 3 shows several variables that might influence retention and compares the differences between those children who remained enrolled in the Healthy Families Program to those who dropped out prior to their one year anniversary.

Asian/Pacific Islander children were less likely to drop out than children in other race/ethnic categories. Families completing the survey in a language other than English were less likely to drop out of the Healthy Families Program.

There was no difference in retention between children with a personal physician versus those without. However, those reporting problems getting necessary care and incidents of foregone health care were slightly more likely to drop out of the Healthy Families Program.

Children with and without chronic health conditions were retained at the same rate.

Table 2. Children enrolled for one year verses children who dropped out of program prior to one year anniversary

Demographic Variables	Still enrolled after one year	Dropped Out prior to one year anniversary
	(n=6881)	(n=3360)
Race/Ethnicity		
White	13.3%	14.6%
Latino	61.3%	62.0%
African-American	2.1%	2.8%
Asian /Pacific Islander	12.7%	9.8%
Native American	0.4%	0.4%
Not Reported	10.1%	10.5%
Language		
English	41.2%	46.5%
Other	58.8%	53.5%
Had a Personal Physician		
Yes	57.0%	56.9%
No	43.0%	43.1%
Had Problems Getting Care		
Yes	20.4%	22.6%
No	79.6%	77.4%
Reported Incidence of Foregone Care		
Yes	17.3%	19.5%
No	82.7%	80.5%
Reported a Chronic Health Condition		
Yes	8.5%	9.2%
No	91.5%	90.8%
PedsQL™ Total Score		
Parent Proxy-report	81.32	81.39

II - Baseline - Health status profile of children entering the Healthy Families Program

Overall Baseline Scoring

- Prior research shows that healthy children, on average, score **83** on the PedsQL™ 4.0 survey instrument.

Table 3 presents the total number of responses received for each item, and the mean and standard deviation of the PedsQL™ 4.0 scale scores for the total baseline sample.

Table 3. Baseline PedsQL™ 4.0 Scores Child Self-Report and Parent Proxy-Report

Scale	Number of Responses Received	Mean	SD
Parent Proxy			
Total Score	10,066	**81.38**	15.90
Physical Health	10,050	83.26	19.98
Psychosocial	10,067	80.25	15.82
Emotional	10,044	80.28	16.99
Social Functioning	10,036	82.15	20.08
School	8,466	76.91	20.16

- Children enrolled in the Healthy Families Program have experienced health-related quality of life similar to that reported for the general child population.

Results from the baseline period indicated that 18 percent (1,949) of the sample children fell within *one standard* deviation below the mean, while 4 percent (454) fell within *two standard* deviations below the mean.

The authors of the PedsQL™ survey instrument indicate that children who fall below one standard deviation are "at risk". For example, if a child's score falls one standard deviation below the mean, monitoring and possible medical intervention should be considered, while scores two standard deviations below the mean require immediate medical intervention.

Baseline Scores by Selected Demographics

Table 4 contains a summary analysis, delineated, by selected member characteristics (age, language and ethnicity). There was a slight correlation between age and parent proxy-report PedsQL™ 4.0 scores, such as the parents of older children tended to view them as having slightly lower health-related quality of life.

Comparing baseline scores among language groups, parents responding in Spanish report significantly lower PedsQL™ 4.0 scores for their children than do parents responding in English, Korean and Chinese, who in turn report lower scores than parents responding in Vietnamese.

Table 4. Summary PedsQL™ 4.0 Scores by Selected Demographics

Category	Baseline Score	
	Mean	SD
AGE		
Toddler (2-4)	87.47	12.44
Young Child (5-9)	78.05	16.44
Child (8-12)	78.88	16.60
Adolescent (13-16)	79.48	16.38
LANGUAGE		
Spanish	79.23	17.12
English	83.49	14.18
Chinese	83.22	13.91
Korean	82.88	15.82
Vietnamese	87.35	15.57
ETHNICITY		
White	84.53	13.40
Latino	80.44	16.45
Black/African American	82.90	1363
Asian/Pacific Islander	82.32	15.70
Native American	83.75	15.79
Not Reported	81.17	15.77

At Baseline, how did access to care affect perceived health-related quality of life?

Associations between access to services and health-related quality of life (PedsQL™ scores) are described below. Parent reports of instances during the past 12 months when they had problems ***getting care for their child that they or a physician felt was necessary*** were tracked and analyzed to determine the correlation. The following question was posed to parents:

"In the last 12 months, how much of a problem, if any, was it to get care for your child that you or a doctor believed necessary?"

Table 5 shows PedsQL™ 4.0 parent proxy-report scores for children experiencing problems ***getting care*** versus those who did get care in the 12 months prior to enrolling in the Healthy Families Program.

Table 5. PedsQL™ 4.0 Generic Core Scores Problems getting necessary care for the child in the year prior to enrolling in HFP

	No Problems		Yes Problems	
Scale	N	Mean	N	Mean
Total Score	7664	**82.67**	2044	**76.65**
Physical Health	7650	84.43	2042	79.05
Psychosocial	7669	81.62	2042	75.27
Emotional	7648	81.59	2039	75.05
Social Functioning	7647	83.48	2036	77.53
School	6405	78.38	1751	71.74

- There is a correlation between the ability of subscribers to access care and their overall health-related quality of life. In the year prior to enrolling in the Healthy Families Program, approximately 20 percent of the families identified a problem in receiving needed care for their child. Children identified with a chronic condition were twice as likely to experience an access problem.

At Baseline, how did chronic conditions affect perceived health-related quality of life?

Table 6 contains the PedsQL™ 4.0 baseline scores for healthy children and children with a chronic health condition in the sample.

Table 6. PedsQL™ 4.0 Baseline Scores Children with and without a reported chronic condition

Scale	Did not report a chronic condition		Reported a chronic health condition	
Parent Proxy	**N**	**Mean**	**N**	**Mean**
Total Score	8709	**82.32**	831	**73.18**
Physical Health	8696	84.08	830	76.99
Psychosocial Health	8711	81.27	830	71.08
Emotional	8692	81.20	829	71.08
Social Functioning	8690	83.05	824	75.06
School Functioning	7287	78.27	756	65.58

These conditions included, but were not limited to Asthma, Attention Deficit Hyperactivity Disorder (ADHD) and Depression.

Approximately 9 percent of the subscribers surveyed indicated their child had a chronic condition. This observation is important because these children experience significantly lower health-related quality of life along all five dimensions (physical, psychosocial, emotional, social functioning and school functioning), than children who were not reported to have a chronic health condition.

Baseline access to care results for children with and without reported chronic health conditions

In the 12 months prior to enrolling in the Healthy Families Program comparing chronic versus healthy populations, families report they are twice as likely to have problems getting care and receiving care if their child had a chronic condition. The health related quality of life of those children whose parents reported access barriers was significantly less than that of children who did not face these access barriers.

Table 7 compares the number and percentage of subscribers reporting problems getting care by whether the family reports a chronic condition.

Table 7. PedsQL™ 4.0 Generic Core Scores Problems getting care – with and without a chronic health condition

Category	**No** problem getting care	**Yes** problem getting care
Without a Chronic Health Condition		
Number in Sample	6,839	1,644
Percent of Sample	81%	19%
With a Chronic Health Condition		
Number in Sample	513	316
Percent of Sample	62%	38%

Children in the Lowest Quartile

Children were defined in the *lowest quartile* based on PedsQL™ Total Scores at baseline. This cutoff score was 71.74.

Table 8 compares baseline data for children in the *lowest quartile* with children above the *lowest quartile*. The data is for those families who responded to the year 1 follow-up survey.

Table 8. Children in lowest vs. top three quartiles recorded in baseline study.

Category	Lowest Quartile	Top Three Quartiles
Race/Ethnicity		
White	8.1%	14.2%
Latino	66.8%	61.2%
Black/African American	1.1%	2.2%
Asian / Pacific Islander	13.2%	12.2%
Native American	0.3%	0.4%
Not Reported	10.5%	9.7%
Language		
English	29.1%	42.7%
Other	70.9%	57.3%
Had a Personal Physician		
Yes	52.3%	57.8%
No	47.7%	42.2%
Had Problems Getting Care		
Yes	29.0%	16.9%
No	71.0%	83.1%
Reported Incidence of Foregone Care		
Yes	25.1%	14.3%
No	74.9%	85.7%
Reported Chronic Health Condition		
Yes	14.9%	6.5%
No	85.1%	93.5%
PedsQL™ Total Score		
Parent Proxy-report	58.07	88.90

There were differences across race/ethnicity with regard to representation in the *lowest quartile*.

Latino, Asian/Pacific Islander, and race-not-reported children were more likely to fall into the *lowest quartile*. Non-English speakers were more likely to fall into the *lowest quartile*.

Children without a personal physician, who reported problems getting care or who reported incidents of foregone care were more likely to fall into the *lowest quartile*.

While children with a chronic health condition were more likely to fall in the *lowest quartile*, more than half of the children in the *lowest quartile* did not indicate the presence of a chronic health condition. This is important because it illustrates that PedsQL™ scores are not merely a proxy for chronic health condition status.

III – Year 1 - Changes in health status based on enrollment in the Healthy Families Program.

Focus on Children with the Poorest Health Status Profile – Lowest Quartile

As discussed in the prior section describing the baseline study, on average, children entering the Healthy Families Program were considered healthy. We would expect that healthy children who continued enrollment in the Healthy Families Program over the one year period would remain healthy. This assumption was confirmed as overall Total PedsQL™ 4.0 scores remained the same from baseline (81.38) to year 1 (81.32).

With this in mind, the majority of the expected change in health status would be in the lowest quartile, or those children who had the lowest scores in the baseline year. These were the children defined as having the lowest health-related quality of life.

Given this premise, the research team concentrated on the children in the *lowest quartile* -- or those in the greatest need of the comprehensive medical, dental and vision services offered by the Healthy Families Program. A comparison of the baseline to year 1 presents the changes in health-related quality of life for the children in the *lowest quartile.*

Reaching these *lowest quartile* children with improved access and quality of service is a major objective of the Healthy Families Program.

How do children in the *lowest quartile* progress after a year of Healthy Families Program insurance coverage?

For children in the *lowest quartile*, PedsQL™ Total, Psychosocial and Physical scores showed remarkable improvements from the baseline to year 1. Table 9 shows the differences in reported scores for the *lowest quartile.*

Table 9. PedsQL™ Total and Summary Scale mean (standard deviation) scores in lowest quartile for PedsQL™ from baseline to year 1

PedsQL™ (N=1459)	Baseline Lowest Quartile	Year 1	Change
Total	58.09	71.73	13.64
Standard Deviation	(9.6)	(17.0)	
Physical	55.16	72.10	16.94
Standard Deviation	(18.2)	(22.4)	
Psychosocial	59.67	71.18	11.51
Standard Deviation	(10.8)	(16.8)	

The increases in scores were 13.64 points for the PedsQL™ Total scale, 16.94 points for the Physical Functioning scale and 11.5 points for the Psychosocial Summary scale.

As described earlier, if a child's score falls one standard deviation below the mean, monitoring and possible medical intervention should be considered, while scores two standard deviations below the mean require immediate medical intervention.

Scores for children who scored two standard deviations below the mean at baseline (those who required immediate medical attention) showed exceptional gains in health related quality of life. Total, Physical and Psychosocial scores are shown in Table 10.

Table 10. PedsQL Total and Summary Scale means (standard deviations) from baseline to year 1 for children greater than 2 standard deviations below the mean at baseline

PedsQL™ 4.0 n = 263	Baseline	Year One
Total	42.60	66.30
Standard Deviation	(6.19)	(20.19)
Physical	36.06	65.91
Standard Deviation	(12.28)	(25.77)
Psychosocial	46.39	66.12
Standard Deviation	(9.65)	(19.35)

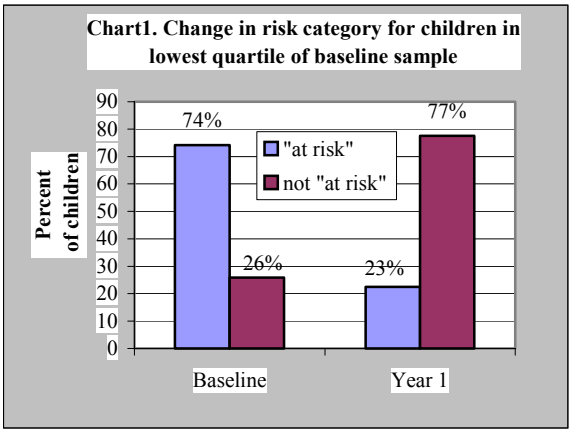
Gains of 24 points (+55%) in total scores were registered from baseline to time 1. Physical scores almost doubled (+83%), while psychosocial scores improved by 20 points (+43%).

This finding reinforces the positive role the Healthy Families Program has played in improving the health status of our most vulnerable subscribers.

Improvements in health- related quality of life through shifting 'at- risk' status

Another way to describe the improvement in health for children in the *lowest quartile* is to examine changes in 'at-risk' status. As described in the baseline analysis, 'at-risk' status is defined as PedsQL™ 4.0 Total Scale score at or below one standard deviation below the mean of the population.

The figures in Chart 1 show for children in the *lowest quartile*, the percent of children in the at-risk category at baseline and year 1. As can be seen, the majority of children in the *lowest quartile* shift from the 'at-risk' category to the 'not at-risk' category, essentially a shift from 75% 'at-risk' at baseline to 25% 'at-risk' status at year 1.



How did the Healthy Families Program influence access to care?

The Healthy Families Program improved access to care for children in the *lowest quartile* and for all children in the program.

Table 11 on the next page shows that both groups of children were more likely from baseline to year 1, to report having a regular physician and less likely to report problems getting care or foregone health care.

From baseline *to* year 1, *lowest quartile* children with a personal physician improved by **9.2** percent, problems getting care decreased by **6.0** percent and families foregoing needed care dropped by **10.1** percent. Similar improvement can also be seen in the entire sample.

Table 11. Percent of children with personal physician reporting problems getting care and reporting foregone care

	Baseline	Time1
Personal Physician		
Lowest Quartile	52.4%	61.6%
Highest Three Quartiles	58.4%	69.0%
Entire Sample	56.5%	67.2%
Problems getting care		
Lowest Quartile	29.0%	23.0%
Highest Three Quartiles	18.4%	15.7%
Entire Sample	19.1%	17.0%
Foregone health care		
Lowest Quartile	25.0%	14.9%
Highest Three Quartiles	15.3%	7.5%
Entire Sample	16.7%	9.2%

Improved access to care related to increases in PedsQL™ scores

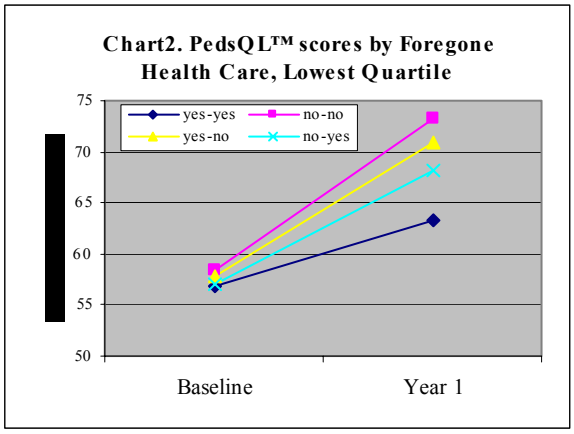
Changes in PedsQL™ scores in relation to reports of foregone health care were examined. Foregone health care is when parents report that there was a time in the last 12 months when they thought that their child needed medical care but they were unable to get it. Children in the *lowest quartile* were delineated into four (4) groups:

1. Children with foregone care at baseline and year 1 (yes-yes).
2. Children with no foregone care at baseline and year 1 (no-no).
3. Children with foregone care at baseline, but not year 1 (yes-no).
4. Children with foregone care at year 1, but not at baseline (no-yes)

As shown in Chart 2, this indicator of not getting necessary care was related to the rate of increase in PedsQL™ scores.

Specifically, while all four groups of children had increased PedsQL™ scores, children with:

- Persistent foregone care (yes-yes) had the smallest rate of increase.
- Children who had recent foregone care (no-yes) had an intermediate rate of increase.
- Children with consistent good access (no-no) or with improved access (yes-no) had the greatest rate of increase.



How did the Healthy Families Program influence chronic conditions?

Going back to Table 8 on page 5, not all children in the *lowest quartile* were those with chronic health conditions, and many children with chronic health conditions fell in the top three quartiles of PedsQL™ scores.

This means that to identify children who are not doing well, it is necessary to know more than whether the child has a chronic health condition.

Examining chronically ill children in the *lowest quartile* group shows these children's scores improved significantly from baseline to year 1.

Table 12 compares PedsQL™ scores for children in the *lowest quartile* with and without a chronic health condition.

Children without a chronic health condition had greater increases in PedsQL™ Total, Physical and Psychosocial scores than children with a chronic health condition.

Table 12. PedsQL™ Total and Summary Scale scores in the lowest quartile Baseline to Year 1 for children with and without chronic health conditions

PedsQL™ Scores	Baseline	Year 1	Change
Total			
Chronically Ill	57.86	65.93	8.06
Not Chronically Ill	58.26	72.84	14.58
Physical			
Chronically Ill	60.58	68.78	8.20
Not Chronically Ill	54.53	72.79	18.26
Psychosocial			
Chronically Ill	56.77	64.34	7.58
Not Chronically Ill	60.24	72.49	12.25

How did the Healthy Families Program influence psychosocial factors?

For children in the *lowest quartile*, PedsQL™ Emotional, School and Social Functioning scores improved from baseline to year 1. These results are shown in Table 13.

Table 13. PedsQL™ Emotional, School and Social Functioning Subscales mean scores in lowest quartile baseline to year1

PedsQL	Baseline	Year 1
Emotional	66.02	72.06
School	55.43	68.59
Social	56.65	71.78

How did the Healthy Families Program influence school performance?

Table 14 presents a detailed breakdown of the school functioning subscale from baseline to year 1 for children in the *lowest quartile*.

Table 14. PedsQL™ School Functioning Subscale item means) at baseline and year 1, for lowest quartile

Subscale Component	Baseline	Year1	Change
Paying attention in class	34.14	57.40	**23.26**
Forgetting things	60.21	68.85	8.65
Keeping up in school activities	36.28	60.89	**24.61**
Missing school because of not feeling well	73.15	77.38	4.22
Missing school to go to the doctor or hospital	72.21	77.12	4.91

As shown, the components most directly correlated to school performance improved by almost 70 percent, ("Paying attention in class" (68%) and "Keeping up with school activities" (68%)). Scores directly related to school and health also improved, but less remarkably.

Did scores differ between race and ethnic groups?

Table 15 shows that within the *lowest quartile*, PedsQL™ scores increased significantly for Latino, Asian/Pacific Islanders and Whites. The limited numbers of responses received from baseline and year 1 for African-American and American Indian make data for these two groups not statistically meaningful.

Table 15. PedsQL™ Total Scale means (standard deviations),from Baseline to Year1, by race/ethnicity

PedsQL™	Baseline	Year 1
Parent Proxy-Report		
White	60.42	69.31
Standard Deviation	(9.62)	(16.61)
Latino	57.42	71.96
Standard Deviation	(9.82)	(17.17)
Asian/Pacific Islander	59.74	73.32
Standard Deviation	(8.56)	(16.55)
Black/African American	Not Reported	
American Indian	Not Reported	

Summary of Key Findings

- **The Healthy Families Program meaningfully improved the health-related quality of life for children in the greatest need.**
  - Most children entering the Healthy Families Program were considered healthy. With this in mind, the majority of the expected change in health status would be in the *lowest quartile*, or those children who had the lowest scores in the base year.
  - Children in the poorest health (*lowest quartile*), as measured through the year one survey results, showed significant improvements in both physical psychosocial and composite health-related quality of life.
  - PedsQL™ scores for this *lowest quartile* increased **25** percent, from **58** to **72**, within the one year period of enrollment.
- **The Healthy Families Program had a positive impact on children with chronic health conditions.**
  - The greatest improvements were exhibited by children with a chronic health condition in the *lowest quartile*, with Total PedsQL™ scores improving from **58** to **66** from baseline *to* year 1.
- **Meaningful improvements in health-related quality of life were achieved within ethnic demographics.**
  - Results comparing the same groups after one year of enrollment indicate the scores for the *lowest quartile* improved "across-the–board".
- **The Healthy Families Program improved access to care for its members.**
  - Improved access to care has a positive correlation to improved health-related quality of life as measured through the PedsQL™ 4.0.
  - From baseline *to* year 1, children with a personal physician improved by **9 percent**, problems getting care decreased by **6 percent** and families foregoing needed care dropped by **10 percent**.
  - In the year prior to enrolling in the HFP, approximately **20 percent** of the families identified a problem in receiving needed care for their child. Children identified with a chronic condition were twice as likely to experience an access problem.
- **Children in the poorest health missed less school and improved school performance due to enrollment in the Healthy Families Program.**
  - PedsQL™ Total school functioning sub-scale scores increased by 24 percent, with remarkable improvements in scores related to "paying attention in class" and "keeping up with school activities".
- **Families participating in the Healthy Families Program are excited about the program and are willing to participate**
  - Of the 10,241 members surveyed during their initial month of enrollment, 6,881 (67%) remained in the HFP. ***Of these 6,881, more than 87% (6,005) completed the second year survey.***

Acknowledgments

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Appendix A – Detailed Description of the PedsQL™ Survey Instrument

PedsQL™ (Pediatric Quality of Life Inventory™) Outcome Measure

The health-related quality of life outcome measure is the PedsQL™ 4.0 Generic Core Scales. The PedsQL™ 4.0 Generic Core Scales include child self-report for ages 5-18 and parent proxy-report for children ages 2-18, and measure the core health dimensions (physical, psychological and social functioning) as delineated by the World Health Organization, as well as role (school) functioning. The PedsQL™ 4.0 Generic Core Scales have been shown to distinguish healthy children and pediatric patients with acute or chronic health conditions, and are related to indicators of morbidity and illness burden.

Previous research and evaluation projects with the PedsQL™ 4.0 have demonstrated a consistent difference between healthy children and children with chronic health conditions, such as asthma, arthritis, cancer, diabetes and cardiac conditions (Varni, Seid, & Kurtin, 2001; Varni, Burwinkle, Katz, Meeske & Dickinson, 2001). Healthy children have been shown to have significantly higher PedsQL™ 4.0 scores than children with chronic health conditions.

The PedsQL™ 4.0 has also been shown to be responsive to interventions of known efficacy, to be sensitive to different levels of disease severity and to have an impact on clinical decision making for pediatric chronic health conditions (Varni, Seid, Knight, Uzark & Szer, in press). Higher PedsQL™ 4.0 scores have also been shown to be positively related to parent report of their children's health care quality.

Design and Calculation of the PedsQL™ 4.0 Generic Core Scales Outcome Measure

The PedsQL™ 4.0 questionnaire encompasses four Scales: 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4) School Functioning (5 items). The PedsQL™ 4.0 questionnaires are comprised of parallel child self-report and parent proxy-report formats. Child self-reports are administered to young children (ages 5-7), children (ages 8-12), and adolescents (ages 13-18). Parent proxy-reports are administered to parents of children ages 2-4 (toddler), 5-7 (young child), 8-12 (child), and 13-18 (adolescent). The parent proxy-report forms are parallel to the child self-report forms and are designed to assess the parent's perceptions of their child's health-related quality of life. The items for each of the forms are essentially identical, differing only in developmentally appropriate language or first or third person tense.

The survey instructions ask how much of a problem each item has been during the past one month. A 5-point response scale is utilized (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Higher scores indicate better health-related quality of life. To create the Total Scale Score (all 23 items), the mean is computed as the sum of the item responses divided by the number of items answered in the Physical, Emotional, Social and School Functioning sub-scales. To create the Psychosocial Health Summary Score (15 items), the mean is computed as the sum of the item responses divided by the number of items answered in the Emotional, Social and School Functioning sub-scales.